

Prepared Statement by Edward F. Kelley III
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at a briefing by the
Energy and Commerce Oversight and Investigations Subcommittee Majority Staff on
Subcommittee's Investigation on Federal Programs Addressing Severe Mental Illness
Thursday May 29, 2014

Severe mental illness is an involuntary illness often times guided by delusions and that person's real belief that he/she is not ill. During our family's 15 year struggle to help our son deal with an illness that he never asked for – we have navigated thru 4 phases: (1) The identification and acceptance that our son had a severe mental illness; (2) Education on proper treatment and care before he turned 18; (3) Dealing with the shock of how laws changed our role when he turned 18; (4) Deciding to come forward and help change our state's and our country's laws.

Our resume as a family includes 15 years navigating the mental health system and coping with the devastation that severe mental illness brings to someone we love. 15 Years of the revolving door of hospitalizations – 7 hospitals in 4 counties and the city. 15 years of him believing he was a US Marshall, CIA, veteran of both Gulf Wars and not believing we were his parents. Over 30 hospitalizations – many times without our knowing where our son went. Years of Judges lecturing us that they will not ‘warehouse our loved one to make life easier for us’; years of the medical and community core services wanting so badly to help us, yet being handcuffed by a system and laws that prevent them from doing their job where it is needed most – for the most seriously mentally ill. And while our family embraced our role as the responsible caretaker – our son's illness rejected our care – **and our laws support his delusions.**

My wife has served on mental health advocacy boards; taught classes full of families clinging to whatever words of hope she can offer them as they start the journey we began 15 years ago. And - ***what she can share with you about what these families have to say – would break your heart and render you embarrassed as to how our country treats its most seriously mentally ill.***

I have testified at both the state level – in nearby Maryland – and at the Federal level – as I am doing today. I participated in the Maryland Department of Health's Continuity of Care Panel hearings in 2013. And the one painful truth that emerged from those difficult sessions and hearings is this – ***there are opposition groups who could care less about my family's plight, or that of the 7 million other families around the country who are connected to us thru tragedy.***

I have personally reached out to consumers – to civil liberties groups – to those in opposition – asking if there was ANYTHING they could do to help families. **I asked if there was anything they could support that would create a system that treats the most seriously mentally ill in a manner different than the vast majority of those who have less severe mental illness.** Not only was there not one inch of movement offered – their testimonies included pointing out that our heartbreaking stories are ‘anecdotal’; threatening lawsuits; claiming unconstitutionality and ***essentially myopically trampling our needs in their efforts to preserve the status quo.***

But times are changing. When I first started testifying in Maryland – most families were reluctant to tell their story – as had ours. It is a gut-wrenching experience and your reward for speaking can be to be summarily dismissed as an insignificant/unworthy player. **But over time, more families are realizing the**

pain of not standing up for what is needed is greater than the pain of publically educating our lawmakers - so that the need for change can be better understood. Families now understand, in no small part because of Congressman Murphy's Bill and efforts of the committee, that the only path to finding solutions is to overcome the opposition thru education, offering up of solutions, participate in the process – regardless of the pain that is incurred by doing so.

This movement is not only staying around – it's growing in leaps and bounds. **BECAUSE WE AS FAMILIES HAVE NO CHOICE.**

While the media often focuses on Sandy Hook; Aurora, Colorado; Virginia Tech, Fort Hood, Columbine and the recent California tragedy – the stories that often fail to be heard are the daily tragedies -

- (1) **HIPPA needs to be changed.** My wife and I have watched health care providers/hospitals hide behind HIPPA, advising they cannot share information w/ us unless our son provides his approval. So we often did not know what hospital our son had been sent to. If we called around, the hospital would say they cannot confirm whether our son was in their care or not. When our son would be released, the hospital would not contact us to advise of his release unless our son gave is permission. Because he would go to different hospitals - there was no coordination of medical history to be provided to the next hospital resulting in our son being a guinea pig; and the medical staff relied on his delusional answers when they developed a treatment plan. With the CRISP system, the medical provider literally removes any mental health information from a person's medical records before entering the information into the centralized data base!
- (2) **We need more hospital beds – and they need to be available for longer stays.** Community hospitals and insurance companies cannot/will not provide intermediate or long term care. Our son was either not admitted, or discharged way too early, because there are no beds available. Our son was either denied care, was shipped to a facility not nearby, or prematurely released time after time. In Maryland, the longer stay facilities operated by the State are overwhelmed with forensic patients - the environment is scary and dangerous. Psychosis is horrific – recovery is difficult – short term stay followed by discharge into the streets makes no sense.
- (3) **AOT needs to become a national standard for alternative treatment & the Dangerous Standard Must Be Expanded.** Imagine the situation as it exists in my state – Maryland. First of all, the goal of voluntary community based treatment, while admirable, is a laughing matter to someone with anosognosia. Not only did our son not seek treatment – he refused treatment. The alternative then is hospitalization – but he refused that course of action as well, so there was a constant struggle to get our son into proper and safe care, thru emergency petitions. The standards for getting someone admitted involuntarily are ridiculously high, and cannot include prior hospitalization history. When he was finally hospitalized, he was released prematurely, and dropped back into society without access to community services - because he refused them. What chance does our son – and so many others loved ones have – with this system?

The opposition cries out that we are creating more stigma if we have AOT – which thousands upon thousands will not seek treatment if AOT comes into play or the dangerousness standard is expanded. **The reality is that those with SMI REFUSE TREATMENT.** Untreated SMI is a slippery slope. Symptoms emerge – often not seen at first – as was the case with our son. Delusions and voices became in charge. Personal hygiene – bathing, hair washing, shaving, clean

clothes – disappear. The person becomes a scary ‘image’. Talking to one’s self; wandering the streets; living under a bridge or under a deck; sleeping outside without proper clothing; having nothing to eat; falling asleep with a lit cigarette on your shirt; being robbed and beaten; all came into play. *When you see this person – you see the essence of stigma – because that is what you imagine – and it is how Hollywood imagines – the face of mental illness. That is real stigma.* Do you think we want our son seen in that light? How about his brother and sister; or cousins or aunts and uncles? How about his grandparents? How about his friends, neighbors, classmates and the community?

This ever growing stigma grows into fear. Isolation from more and more of his support network is inevitable, as the toll of watching someone you care for deteriorate despite everyone’s best efforts takes hold. **All because the person refuses to believe he/she is ill – and it’s a real belief – an impairment of the brain.** So who steps in? **The Family.**

Meanwhile, the ill person gets angrier at his/her family – because he/she us as the ones causing their life to be so bad. That is why the family is so much more at risk. **In reality – our system must be changed so that families are not afraid to come forward when someone they love is in need of help.**

- (4) **Substance Abuse is a Common Companion.** A person with voices and delusions is living a in a virtual hell. They self-medicate with drugs and alcohol. I would venture to say that many people would do the same thing to cope with what can only be described as an unbearable existence. *Once substance abuse becomes a part of the journey, the danger levels grow immensely. Psychosis and drugs – bad combination. We need a dual focus and approach.*

This Bill is labeled ‘The Helping Families in Mental Health Crisis Act’ not just because the families need help in changing a broken system. **YOU** need this bill. As does your family, neighbors, schools, workplaces, malls – because YOU are at risk when the core support for the most seriously mentally ill are prevented from doing their job. When you put your head on the pillow tonight – ask what you would want for your family if severe mental illness came into your life? What if your child has a beautiful baby boy – and you watch helplessly as your own child goes thru unbearable hell trying to help their child – your grandchild. Or if it were your mom or dad? Or sister or brother? Or your precious child? *Ask yourself what will happen in communities if and when a family give up?*

I would like to make a public appeal to Senator Barbara Mikulski – to join this cause – to embrace its purpose. You did just that with Alzheimer’s. You would never want your grandparent or mom with Alzheimer’s to live under a bridge or be exposed to the harsh winter elements without proper clothing or access to food – just as we do not want that for our son. Part of this Bill has already passed and has become law. **We now need the appropriation committee to fund the Grant Program for AOT.**

To our lawmakers here in Washington D.C.: Families know first and care the most. Give tools of empowerment to families. Stop being afraid of the wrong things. Be afraid of severe mental illness’ impact on you, your loved ones, your friends, your neighbors and others. If you lived but one day with a loved one with psychosis – which I pray never happens – you would get this bill passed tomorrow.

Respectfully submitted this 29th day of May, 2014
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